Aid in Dying:
History & Background for Students, Activists and Professionals

Compassion & Choices
P.O. Box 101810
Denver, CO 80250
1-800-247-7421
info@compassionandchoices.org
www.compassionandchoices.org
Introduction

Spending one’s final days in an ICU, because of terminal illness is for most people a kind of failure. You rely on a ventilator, your every organ shutting down, your mind teetering on delirium and permanently beyond realizing that you will never leave this borrowed, fluorescent place. The end comes with no chance for you to have said goodbye or “It’s O.K.” or “I’m sorry” or “I love you.”
– Atul Gawande, The New Yorker

Approximately 2.5 million people die each year in the United States. Of those, 1.5 million were diagnosed with terminal illnesses. Nearly 70 percent of us will spend our final days in hospitals, nursing homes or hospice, where important decisions must be made about treatment in the final stage of our lives. Yet dying, and preparing for it, rarely appears in public or even private conversations in our society.

Medical advances have prolonged the quantity of our days, but not necessarily their quality. More people than ever before spend their final hours incoherent, sustained by pain medication and machines, often against their wishes.

Many Americans are divided over costly medical interventions vs. providing a legal means for the terminally ill to end their own suffering.

We face a modern dilemma: How should we die, when there are so many ways to postpone death?

This guide is designed to clarify some of the most common questions that arise around aid in dying. The practice is gaining wider acceptance: It is now authorized in Oregon, Washington, Vermont, Montana and New Mexico. There are legislative and ballot initiative campaigns in many other states to enact similar death-with-dignity laws, and it may only be a matter of time before the practice is authorized throughout the country.

Please note this guide is a work in progress and is updated as new questions are asked, as changes in the law occur and as new data is released from those states where the practice is authorized. If you have a question that is not answered here please feel free to contact us for more information.
A Note on Terminology

Exactly who coined the phrase "physician-assisted suicide" is unclear, but for a time it seemed an accurate enough description: a physician providing a suffering patient with a prescription for a life-ending medication that the patient could then self-administer to bring about a peaceful death. However, as the debate over legalizing this practice as an accepted medical procedure evolved, it became clear that “suicide” was not an accurate term to describe the rational and deliberative process that went into a terminally ill person’s decision to end their suffering.

Suicide is about choosing death over life, and often has some underlying condition or cause, for example depression, which if identified and properly treated can allow the person to live a full life. On the other hand, a terminally ill person is actively dying and therefore no longer is choosing death over life, but rather one form of death over another.

In 2006, the Oregon Department of Human Services (ODHS), which oversees reporting of deaths under the Oregon Death With Dignity Act, announced it would discontinue using the term “physician-assisted suicide” and instead will use the term “deaths under the Oregon Death With Dignity Act.”

In November of 2006, the American Public Health Association passed a resolution recommending use of the phrase “aid in dying” or “patient-directed dying,” and the American Medical Women’s Association also rejected the term “suicide” to describe this process. The American Academy of Hospice and Palliative Medicine (AAHPM) adopted the term “physician-assisted death,” noting “that it captures the essence of the process in a more accurately descriptive fashion than the more emotionally charged designation physician-assisted suicide.” Other organizations are following suit by using more accurate, neutral and less emotionally charged terms such as “aid in dying” whenever possible.

<table>
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<tr>
<th>Correct Language:</th>
<th>Incorrect Language:</th>
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<tr>
<td>Aid in dying or death with dignity.</td>
<td>Assisted suicide or euthanasia.</td>
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Definitions

There is much confusion over the language used to describe end of life options, and many of these terms are not universal in their definitions. Below are some of the most commonly confused terms:

**Advance directive** - This legal document, properly called an advance healthcare directive, is comprised of two (or more) parts, the first being a “living will” and the second being a “durable power of attorney for healthcare.” In the case of the living will, people can outline in writing their end-of-life medical treatment preferences in the event they are no longer able to communicate for themselves. The **durable power of attorney** allows people to appoint another person, called a healthcare agent or proxy, to make medical decisions on their behalf, but again only if they are unable to communicate for themselves.

**Aid in dying** - the process that allows a mentally competent, terminally ill adult to legally request a prescription for a life-ending medication from their physician. The medication must be self-administered.

**Death with dignity** refers to both a concept and a movement; in both cases it includes the ideas of limiting suffering and providing control and choice at the end of life. In most cases, death with dignity also includes support for a mentally competent, terminally ill patient to request a lethal dose of a drug to accelerate their death.

**Death With Dignity Act** - The current laws in Oregon, Washington and Vermont allow a competent, terminally ill adult the right to ask his or her physician for a prescription for a life-ending medication that the patient can then take to accelerate death.

**Double-effect** - The possibility that efforts to relieve a person’s pain and suffering may also unintentionally bring about the person’s death. In theory double-effect differs from physician aid in dying because the intent of the physician is only to relieve the person’s pain and suffering, even if the death is a foreseeable result (for example see palliative sedation).

**Euthanasia** - The intentional ending of a person’s life upon their request, performed by a physician or other medical healthcare professional, and usually by lethal injection. Euthanasia is illegal everywhere in the United States and is not a practice Compassion & Choices supports.
**Palliative care** - Sometimes called “comfort care,” palliative care is aimed at relieving a person’s physical and sometimes emotional pain through medication, physical therapy, spiritual counseling or other methods, and with the understanding that the treatment is not intended to cure or prolong the person’s life.

**Palliative/total sedation (see also terminal sedation)** - The continuous administration of medication to relieve severe, intractable symptoms that cannot be controlled while the person is conscious. This state is maintained until death occurs.

**Terminal illness** - Describes an irreversible and incurable illness for which the medical expectation is death. The federal definition of “terminally ill” is defined as a probable life expectancy of six months or less, which triggers Medicare of Medicaid expense reimbursement for the patient’s hospice care.

**Voluntary stopping of eating and drinking (VSED)** - The conscious refusal to accept fluids or nutrition. This procedure is gaining in popularity and acceptance as a method of hastening death because the process seems more natural, especially when considering patients nearing death naturally lose their desire to eat and drink. Studies have reported that aside from initial thirst, which can be managed, the resulting death takes two weeks or less, and is usually a peaceful one (Ganzini, et al., 2003). This is usually more distressing for the family and loved ones than it is for the patient, who generally lapses into a coma-like state following several days without fluids.

### A Brief History of the Death With Dignity Movement

Historically, death has come quickly: Diseases struck with little warning and suffering did not typically last long. More people died from easily preventable diseases such as tuberculosis, influenza and cholera. Modern medical advances have changed that, at least in developed countries like the United States. In the last 100 years, life expectancy here has increased from 50 years to 79 years. The 1950s introduced medical advances such as open-heart surgery, organ transplants and penicillin. People were living longer, retiring later, and what once was considered “elderly” was classified as “middle-aged.”
With longer life spans came the emergence of degenerative age-related diseases such as Alzheimer’s, stroke, and arthritis, creating a need for hospitals and nursing homes where people were sent to die rather than be cured. More people died after comparatively prolonged struggles with “terminal” illnesses. Living longer is not always living better, and the quest for the quality of life versus its quantity has grown.

**Early Attempts to Improve End-of-Life Choices**

- The first attempt at authorizing an individual’s right to end his or her own life with the help of a physician was presented to the Ohio legislature in 1906, where it was promptly defeated.

- In 1938, the Euthanasia Society of America was founded; but being too radical for its time, the Society ultimately changed its focus to confront the issues of informed consent and the right to refuse unwanted medical treatment.

**Matter of Quinlan (1976):**

- Karen Ann Quinlan was just 21 years old when she stopped breathing from what is believed to have been an overdose of drugs and alcohol and she fell into a comatose state; unable to breathe without the aid of a respirator. When it became apparent she would never regain consciousness, her parents asked that her respirator be removed. Her physicians refused, claiming that discontinuing life support would result in her death, and under the laws that existed at the time, this would have been manslaughter. The Quinlan case eventually found its way to the New Jersey Supreme Court.

- In a dramatic shift in the ethical debate around patients’ rights, the court decided in favor of Karen Quinlan’s parents, and in 1976 her doctors removed Karen’s respirator. Unexpectedly, she was able to breathe independently and lived in a coma until 1985, when she ultimately died of pneumonia.

- In ruling on behalf of the parents, the New Jersey Court for the first time recognized that a patient
(or in this case a designated family member) and not a paternalistic medical professional, was in the best position to make decisions as to the type of medical care and treatment that was appropriate, even if such decisions included the withholding or withdrawal of life-sustaining equipment. This “shift in power” would rapidly change the physician/patient relationship and the way medicine was practiced.

Aid-in-Dying Advocacy Groups Form

- The Hemlock Society formed in 1980 with the purpose of educating the public about the worsening state of dying in America, while simultaneously working to pass laws that would offer patients the legal option of aid in dying if their suffering became intolerable.

- In 1993, Compassion in Dying was founded in Washington state to offer comfort and support to terminally ill people and their families including providing information on humane and safe methods to accelerate their deaths. An important goal was to help individuals avoid what otherwise might be painful and potentially violent deaths.

- In 2003 Hemlock changed the name of its parent organization to End-of-Life Choices, which merged with Compassion in Dying in January of 2005 to become Compassion & Choices. Other grassroots “right-to-die” groups have formed in cities across the country, some merely acting as conduits for education, others offering information on effective methods of aid in dying.

Early Efforts to Pass Aid-in-Dying Laws

- Throughout the 1990s and 2000s, legislative bills and voter initiatives aimed at legalizing aid in dying were introduced at the state level in Washington, California and Michigan.

- After several unsuccessful attempts, a 1994 ballot initiative narrowly succeeded in Oregon in a 51% to 49% vote, making it the first state to legalize aid in dying under an extensive list of regulations designed to prevent misuse and abuse.

- Challenges from religious and right-to-life groups delayed implementation of the law and resulted in a second voter initiative being placed on the ballot in 1997, this one aimed at repealing the
1994 law. This also narrowly succeeded, again in a 51% to 49% vote, and the Oregon Death With Dignity Act went into effect in 1998.

- In November of 2008, voters in the state of Washington passed an aid in dying law modeled after Oregon’s Death With Dignity Act by a margin of 58 to 42 percent.

- In December of 2008, a circuit court in Montana ruled that the state’s constitutional protections granting Montanans the individual right to dignity and privacy included the right of a terminally ill adult to request a prescription for a life-ending medication, thus making Montana the third state to permit legal aid in dying, despite strong opposition.

- In 2013, Vermont became the first state to authorize aid in dying through the legislative process.

- In 2014, a district court ruling in New Mexico held there was a constitutionally protected right to aid in dying.

Detractors of Aid in Dying

- Some religious denominations state that all life is sacred and that only God can decide when someone’s life should end, even when the person is in a comatose state without any hope of ever regaining consciousness.

- Leaders of the Roman Catholic Church and leadership from other religious institutions have contributed tens of millions of dollars toward defeating death with dignity efforts in other states and in trying to overturn the Oregon law (Hillyard & Dombrink, 2001).
While church leaders continue to work steadfastly against death with dignity, polling shows similar levels of support among the faithful as in the broader population: about 65% in favor.

Leadership among people with disabilities is also visibly opposed to death with dignity laws because of a stated belief that support for aid in dying might cause some people to devalue lives of the disabled. Again, these attitudes are prevalent among organized leadership, while studies show support for death with dignity among disabled people that is similar to the general population.

The American Medical Association, state medical associations and other medical groups continue to have a firm plank against aid in dying. Medical associations are often among the most visible detractors of death-with-dignity laws. However, several notable medical groups support the practice, including the American Medical Student Association, American Medical Women’s Association, and the American College of Legal Medicine, among others.

The Movement Continues to Grow

Despite the opposition, there is a growing desire for decriminalization of aid in dying. Polls consistently show public support in the mid 60% to 70% range, and none of the “catastrophes” opponents predicted would happen when Oregon’s law took effect ever occurred, further demonstrating that under safeguards and controls legalization can, and does, work.

Chronology of the Aid-in-Dying Movement

The chronology of the choice-in-dying movement in the United States can be traced back as far as the early 1900s. The movement made major strides throughout the 1990s, which ultimately led to significant changes at the bedside, in the courtroom, and in state and federal government. A diverse group of people, some acting together and many working individually, wrote books, gave speeches, advocated for new laws, and assisted friends and family members in finding their way through wrenching end-of-life decisions.
Timeline

1906 A euthanasia type bill is introduced into the Ohio legislature but is immediately defeated.

1938 The Euthanasia Society of American is founded in New York, but later changes its focus to prevented prolonged and unwanted medical treatment in seriously ill patients.

1967 A right-to-die bill is introduced in the Florida legislature. It arouses extensive debate but is unsuccessful.

1976 In the Matter of Quinlan, the New Jersey Supreme Court rules that when clear evidence exists that a person would not want to be kept alive by artificial means that the cessation of life support could be authorized. California becomes the first state to pass a “natural death act” that allows a person to state in writing their desire not to be maintained by artificial means where there is no hope for their recovery.

1980 The Hemlock Society, an end-of-life care organization for those suffering with incurable illnesses, is formed. It later evolves into End-of-Life Choices (EOLC). Subsequently, in 2005 EOLC merges with Compassion in Dying to form Compassion & Choices.

1987 Oregon Senator Frank Roberts sponsors legislation championing choice at the end of life.

1990 The U.S. Supreme Court decides the Cruzan v. Director, Missouri Department of Health, ruling that Missouri was permitted to require clear and convincing evidence of the wishes of a patient regarding provision of artificial nutrition and hydration. This affirmed the right of Americans to refuse unwanted medical treatment, and their right to appoint a health care proxy to speak for them when they could not.

1991 Ballot measure I-119 to allow mentally competent, terminally ill patients assistance in dying is voted on in Washington state. Initiative 119 fails by narrow margin. Derek Humphry, founder of the Hemlock Society, publishes the
first edition of Final Exit: The Practicalities of Self-Deliverance for the Terminally Ill.

1992 Proposition 161, the California Death With Dignity Act, narrowly fails.

1993 Compassion in Dying is founded to provide support and advocacy programs for terminally ill individuals in Washington state.

1994 Compassion in Dying develops and files two federal lawsuits asserting that a mentally competent, terminally ill adult has a right protected by the U.S. Constitution’s guarantees of liberty, privacy and equal protection to choose aid in dying. The first case is filed in Washington state and is known as Glucksberg v. Washington. The second case is filed in New York and is known as Quill v. NY. The Federal District Court for the Western District of Washington held for the plaintiffs. The state of Washington appeals to the Ninth Circuit Court of Appeals.

Oregon voters approve Measure 16, the Oregon Death With Dignity Act, a ballot initiative that permits terminally ill people, under proper safeguards, to obtain a physician’s prescription to end life in a humane and dignified manner. The law passes with 51 percent of the vote. Co-author and chief petitioner is Barbara Coombs Lee, President of Compassion in Dying and subsequently Compassion & Choices.

1996 The Ninth Circuit Court of Appeals (in Glucksberg v. Washington) and the Second Circuit Court of Appeals (in Quill v. NY) both find that the U.S. Constitution protects the choice of a competent, terminally ill patient to choose aid in dying. The states of New York and Washington file for review in the U.S. Supreme Court.

1997 The Compassion in Dying Federation is formed by Compassion in Dying of Washington, expanding to launch national advocacy and support programs.

Oregon’s law is challenged by the National Right-to-Life Committee. The challenge was held up in the courts until it was dismissed by the Ninth Circuit Court in 1997. That year, the Oregon legislature put a measure on the ballot to rescind
the law, but it was defeated by 60 percent of the voters.

In Glucksberg v. Washington and Vacco v. Quill, the U.S. Supreme Court declines to find federal constitutional protection for aid in dying, leaving the possibility open that it will do so in the future, and refers the issue to the “laboratory of the states.” The court recognizes a federal constitutional right for dying patients to receive as much pain medication as necessary to obtain relief, even if this advances time of death.

The Hemlock Society establishes the Caring Friends program to provide information and support to its members.


States consider enacting death with dignity laws, including Hawaii, Vermont and California. Strong, well-funded opposition from the Catholic Church, right-to-life advocacy groups and some disability advocacy groups are successful in defeating measures despite strong public support.

Oregon Death With Dignity Act begins implementation.

Compassion In Dying’s client “Helen” becomes the first person to take medication under Oregon’s law.

1999 The U.S. House of Representatives passes the Pain Relief Promotion Act (PRPA). The bill would have criminalized aid in dying and nullified the Oregon law.

2000 Oregon Sen. Ron Wyden’s threatened filibuster keeps the PRPA from reaching the Senate floor.

Compassion in Dying Legal Director, Kathryn Tucker, represents the Bergman family of California in bringing the first case in the nation to claim that failure to treat pain adequately constitutes elder abuse, winning $1.5M verdict for patient’s pain and suffering. The case establishes that failure to treat pain adequately can result in significant financial risk to healthcare providers.

Compassion in Dying drafts and sponsors legislation passed in California (AB 487), requiring that physicians receive continuing education in pain management.

2002 October 6 marks the fifth anniversary of Oregon’s Death With Dignity law; 129 terminally ill Oregonians have used it to die peacefully.

Attorneys present oral arguments for Oregon v. Ashcroft arguing states’ rights. Months later, Judge Jones rules against Ashcroft and rebukes the federal government for its attempt to “stifle an ongoing, earnest and profound debate in the various states concerning physician-assisted suicide.”

2003 The Hemlock Society evolves to become End-of-Life Choices.

2004 The Department of Justice appeals Oregon v. Ashcroft to the United States Ninth Circuit Court of Appeals. The Ninth Circuit Court affirms the lower court, leaving the Oregon Death with Dignity Act intact.

As Attorney General John Ashcroft resigns, he files an appeal to the U.S. Supreme Court to review the Ninth Circuit’s affirmation of lower court injunction of the Ashcroft directive. Now known as Gonzales v. Oregon, the case asks the high court to consider whether the federal Controlled Substances Act authorizes the Department of Justice to displace state regulators and determine legitimate use of medications. Traditionally, this prerogative has been reserved for the states.

2005 Compassion in Dying and End-of-Life Choices unify to become Compassion & Choices. The new organization maintains headquarters in both Denver and Portland, and is the largest
organization in the United States advocating for patients’ rights at the end of life.

**2006** American Medical Women’s Association (AMWA) adopts policy in support of aid in dying.

Compassion & Choices’ Spokespeople, Steve Mason and Tom McDonald, give testimony in California State Assembly in support of California initiative AB 374, the California Compassionate Choices Act, which later fails by narrow margin.

**2007** American Public Health Association (APHA) adopts policy, “Supporting Appropriate Language Used to Discuss End-of-Life Choices.”

In October, Compassion & Choices Legal Director Kathryn Tucker and Missoula litigator Mark S. Connell file *Baxter v. Montana* on behalf of Bob Baxter, Montana physicians and Compassion & Choices, asserting that the Montana State Constitution protects a peaceful death with dignity.

The Washington State Psychological Association (WPSA) approves policy regarding value-neutral terminology regarding end of life choices.

**2008** American Medical Students’ Association adopts policy reiterating and broadening support of Aid in Dying. Ten years of data from Oregon begins to inform discussion about impact of legal aid-in-dying option. All reports indicate that the law works well with no evidence of abuse.

Washington Initiative 1000, modeled after Oregon’s Death with Dignity Act, qualifies for November 2008 ballot.

A bill developed by Compassion & Choices designed to ensure that terminally-ill patients have access to information about a full range of end of life choices accepted in law and medicine passes in California: AB 2747, the Right to Know End-of-Life Options Act. On September 30, 2008, Gov. Schwarzenegger signs the Terminal Patients’ Right to Know End-of-Life Options Act, AB 2747 (Berg-Levine).
American Public Health Association (APHA) adopts a position supporting death with dignity for terminally-ill patients.

On November 4, 2008, Washington voters overwhelmingly approved I-1000 59% to 41%. Washington becomes the second state to authorize aid in dying. The Yes on I-000 campaign has moved patient’s rights forward. The Oregon experience shows aid in dying law benefits all at end of life. It provides comfort and control to the terminally ill and ends violent deaths.

Montana District Court Judge Dorothy McCarter held in December 2008 that the Montana State Constitution protects a peaceful death with dignity making Montana the third state to provide its residents with legal aid in dying. Compassion & Choices Legal Director Kathryn Tucker and Missoula litigator Mark S. Connell led the successful Baxter et al v. Montana case, filed October 2007.

2009 On January 1, the Terminal Patients’ Right to Know End-of-Life Options Act, AB 2747 (Berg-Levine) goes into effect in California.

Compassion & Choices calls on the Obama Administration to repeal last-minute regulations allowing denial of medical services based on health care worker religious beliefs.

On March 5, Washington’s Death With Dignity Act begins implementation.

As the health insurance reform debate heats up in Washington and around the country, Compassion & Choices aggressively responds to misinformation campaign launched by opponents of end-of-life choice to undermine a key provision of health insurance reform. Recent action and statements indicate the end-of-life consultation provision may survive in a final healthcare bill.

On October 7, Compassion & Choices files suit in Connecticut on behalf of two Connecticut physicians, Gary Blick and Ron Levine, asserting that the Connecticut statute which makes a crime of assisting someone to “commit suicide” does not reach the conduct of a physician who writes a prescription for a life-ending medication for a terminally ill patient.
On October 29, Congressman Earl Blumenauer of Oregon stood with leaders of the House of Representatives as they unveiled House Resolution 3200, Section 1233, the Life-Sustaining Treatment Preferences Act of 2009 that would provide coverage under the Medicare Program for consultations regarding POLST.

Senator Jay Rockefeller champions end-of-life care in his report to the Senate Finance Committee’s healthcare reform legislation. Compassion & Choices continues work to assure end-of-life choice remains a key component of final health insurance reform package.

On October 13-14, Compassion & Choices hosts “Dignity & Choices, A Symposium on End-of-Life Advocacy” in Washington, D.C. Two days of discussion, exploration and study, Dignity & Choices provides an opportunity to promote principles and practices that focus on patients. Physicians, social workers, nurses, attorneys and advocates for end-of-life choice filled the National Press Club to hear aspects of end-of-life care rarely discussed and illuminate the way forward.

On December 31, the Montana Supreme Court rules that it is not against public policy of the state of Montana for a physician to provide aid in dying to a mentally competent, terminally ill individual.


On June 2 Blick et al v. Connecticut is dismissed without reaching the merits, on sovereign immunity grounds, denying plaintiffs the opportunity to make their case to distinguish committing “suicide” from a mentally competent terminally ill patient ingesting medications to bring about a peaceful death.

New York passes the Palliative Care Information Act (PCIA) in August. The law, drafted by Compassion & Choices and modeled after a similar measure in California, requires healthcare
workers to provide information and counseling on end-of-life options.

Compassion & Choices files the groundbreaking lawsuit *Hargett v. Vitas* seeking accountability for the unnecessarily painful death of 43-year-old mother of three, Michelle Hargett-Beebee, who was never informed of the availability of palliative sedation. This is the first case in the nation to allege that failure to tell a patient about palliative sedation falls outside the standard of care.

**2011** Legislative opponents introduced SB 116 in Montana to nullify the Montana Supreme Court’s landmark ruling in *Baxter v. Montana*, a case litigated by Compassion & Choices. The Montana Medical Association testified in official opposition to the measure. On February 16 the Montana Senate Judiciary Committee declined to adopt this measure, preserving the option of aid in dying for Montanans.

A bill amending Washington’s Death With Dignity Act, SB 5378, fails to pass out of committee, in response to Compassion & Choices proactive efforts and voter support. SB5378 would have amended the section of Death With Dignity Act specifying deaths under the Act do not constitute “suicide.”

Compassion & Choices launches successful public campaign throughout Oregon to defeat HB 2016, a bill requiring all terminally ill patients who request aid in dying to undergo psychiatric evaluation. The Oregon House HealthCare Committee holds no hearing or work session on HB 2016.

**2012** Dr. Peter Goodwin, longtime Compassion & Choices advocate who played a leading role in crafting and promoting Oregon’s Death With Dignity Act, uses the law to end his life at age 83 after suffering with a rare brain disease, corticobasil degeneration.

With plaintiffs Dr. Katherine Morris and Dr. Aroop Mangalik, Compassion & Choices files a lawsuit, *Morris v. New Mexico*, asserting that aid in dying is not prohibited by existing New Mexico law.

Compassion & Choices gains membership in the Leadership Conference on Civil and Human
Rights in Washington, D.C., the nation’s premier civil and human rights coalition.

The Montana Board of Medical Examiners issues a statement confirming it will consider aid in dying as it would any other medical procedure when evaluating physician conduct in the state, rebuffing an effort to chip away at the recognition of the legality of aid in dying in Montana.

2013 Opponents of choice in Montana introduce House Bill 505, dubbed the “Doctor Imprisonment Act,” which would send doctors to prison for ten years for providing aid in dying. Compassion & Choices kicks off an aggressive campaign that results in defeat of the bill.

Compassion & Choices launches a campaign to end unwanted medical treatment, and Chief Operating Officer Mickey MacIntyre brings the issue to the influential Institute of Medicine’s Committee on Transforming End-of-Life Care during its first meeting February 20.

Compassion & Choices expands its campaigning for death-with-dignity laws, with progress in several states:

- The New Jersey Assembly Health and Senior Services Committee approved a death-with-dignity bill February 7, 2013.

More than 100 people testified in support of the HB 6645, a death-with-dignity bill in Connecticut, with the last witness testifying at 1:30 a.m. Knowing that the bill would clear committee, opponents threatened a filibuster, halting the bill for the 2013 session.

On May 20, Vermont becomes the fourth state to legalize aid in dying and the first in the nation to do so through the legislature. Compassion & Choices President Barbara Coombs Lee calls the law “a political breakthrough that will boost support for death-with-dignity bills nationwide.” Compassion & Choices supported Patient Choices Vermont in getting the law passed and immediately began working to implement the law, providing education and assistance to members of the public and medical professionals.
Compassion & Choices files a civil suit, *Hallada v. Lakeland*, against Lakeland Regional Medical Center and Oakbridge Healthcare Center for failure to honor 91-year-old Marjorie Mangiaruca’s advance healthcare directive in their aggressive efforts to resuscitate her.

The Pennsylvania Attorney General charges Barbara Mancini with assisted suicide in the death of her 93-year-old, terminally ill father, Joe Yourshaw, whom Barbara was caring for while he was dying in at-home hospice care. Compassion & Choices ignites a nationwide discussion on end-of-life autonomy through its campaign to have the charge dropped.

2014 In February Judge Jackqueline L. Russel dismissed the case against Barbara Mancini, stating the prosecution failed to prove a crime had been committed.
Most Commonly Asked Questions

Who Is Compassion & Choices, and what does your organization do?

Compassion & Choices is the nation’s oldest and largest nonprofit organization working to improve care and expand choice at the end of life. The organization is non-judgmental, affirmative and inclusive. Compassion & Choices was formed in January of 2005 following the unification of the nation’s two best-known and respected choice-in-dying organizations: Compassion in Dying and End-of-Life Choices (Originally formed as the Hemlock Society). Our mission consists of the following core areas:

Support: Compassion & Choices’ consultation program uses the power of choice and comfort to restore hope to individuals and their loved ones at the end of life. Our professional staff and trained volunteers help thousands of clients each year by listening without judgment to their fears and guiding their search for a peaceful, humane death. We help clients with advance directives, local service referrals, and pain and symptom management. We offer information on self-determined dying when appropriate and provide emotional support through difficult times.

Educate: Compassion & Choices promotes informed end-of-life decision-making by educating the public and advising healthcare professionals. We employ educational training programs, media outreach and online and print publications to change healthcare practice, inform policymakers, influence public opinion and empower individuals.

Advocate: Compassion & Choices devotes itself to creative legal and legislative initiatives to secure comprehensive and compassionate options at the end of life. We set national standards for end-of-life care and assert constitutional protection for aid in dying. Our team of litigators and legislative experts fights bills that would force patients to endure futile, invasive treatment; sets enforceability standards for advance directives; mandates pain and palliative care training for physicians; monitors legislative and policy initiatives; and ultimately shapes best-practice standards for end-of-life care.
What is your position on euthanasia?

We do not support active euthanasia, a procedure where a physician or other medical person administers a lethal dose of medication to a patient, most often by injection. What we do support is aid in dying, the legal right for a terminally ill adult to ask his or her physician to write a prescription for a life-ending medication that the patient can self-administer when, and if, their suffering becomes unbearable. The difference is that with euthanasia control rests in the hands of a third party, whereas with aid in dying, the control remains in the hands of the patient at all times.

How is terminal sedation any different from euthanasia?

Some people argue that there is a no difference because in either case the patient’s death is foreseeable; it’s only a matter of whether death occurs immediately (as in the case of euthanasia) or over a longer period of time (as in the case of terminal sedation where the patient is placed in a comatose state, after which all further life support is removed or withheld). Others argue that with euthanasia the doctor causes the patient’s death, whereas with terminal sedation or withholding or withdrawal of life support the patient is simply being allowed to die from his or her underlying illness. Opponents argue that the former is “killing” whereas the latter is simply allowing nature to take its course. This “difference” argument has been going on for years and will probably never be resolved.

Why do the terminally ill people seek this form of help?

Terminally ill patients are not as interested in accelerating death as they are in knowing that there is an option to a peaceful and humane death should all other efforts to relieve their suffering fail. Studies from over fifteen years of data in Oregon reveal that as long as patients know an option of last resort exists, around 90 percent of patients initially interested in accelerating their death are willing to try alternative forms of treatment. Of those who receive a prescription, about a third never use it.

Among those who ultimately decide to take the medication, the most frequently cited reason is the loss of autonomy they experience and the deterioration of
their physical condition causing them to become dependent upon some form of life support. For some patients, particularly those dying from cancer, they prefer to accelerate their death when it reaches the point where the only way to relieve their pain is through such high doses of medication that they are no longer able to coherently communicate with their loved ones.

Does a patient have the right to refuse unwanted medical care or treatment?

YES. It is well settled by the U.S. Supreme Court that a competent adult has the right to refuse unwanted medical treatment. This could include life-saving surgery, removing or withholding artificial life support, the voluntary stopping of eating and drinking (VSED), discontinuing dialysis, refusing antibiotics to combat a life-threatening infection, and the list goes on.

Paving the way for the right to refuse treatment were the Jehovah’s Witnesses and their belief against blood transfusions. Christian Scientists similarly refused all forms of medical treatment. The only time courts would intervene is when the patient was a minor and therefore presumably unable to make informed decisions, where the patient was pregnant and the life of the unborn child could be affected, or when a patient lacked the mental capacity to make rational informed decisions.

A year after the U.S. Supreme Court re-affirmed the right to refuse unwanted medical treatment in the case of *Cruzan v. Director*, the Patient Self-Determination Act of 1991 was passed. Although this law only affects hospitals and healthcare institutions that receive federal funding (such as Medicare and Medicaid reimbursement), it solidified a person’s Constitutional right to self-determination.

How do physicians feel about aid in dying?

Among the medical community support for aid in dying exceeds 50 percent. A March 2005 poll announced that “a national survey of 1,000 physicians revealed that a clear majority of physicians (57%) believe that it is ethical to assist an individual who has made a rational choice to die due to unbearable suffering, while 39% believe it is unethical.” (5% had no opinion on the issue). This does not necessarily mean that over half of all doctors would themselves participate if asked by a patient, but rather they would support a patient’s right to make their own healthcare decisions. And aid in dying is supported by
the American Medical Students Association (AMSA), the American Medical Women’s Association (AMWA), the American College of Legal Medicine and the American Public Health Association, to name a few of the more prominent professional medical organizations.

Do doctors have to assist a patient?

NO. The Oregon and Washington laws make participation voluntary. Any physician, pharmacist or healthcare facility opposed to aid in dying is not required to participate. Similarly, only an individual him or herself can initiate a request for help.

What is a nurse’s role in physician aid in dying?

Nurses are sometimes with the patient at the time they decide to take the medication. People who use aid in dying often have friends and/or family present, and the nurse might act as a guide, simply explaining what is happening and reassuring the family that what they are seeing is the “normal” process that death takes.

Studies have found that nurses are the ones most likely to be asked by a patient or the patient’s family for help in dying. For many doctors death represents failure and they may try to distance themselves from the reality, leaving the nurse to function as the primary provider of medical care. Fortunately some medical schools are now offering classes in death and dying, and hopefully more doctors will begin to accept that death is inevitable and should therefore be managed and not avoided.

Wouldn’t improvements in end-of-life care make the need for aid in dying go away?

Not necessarily. Doctors are reluctant to prescribe adequate pain medication for a number of reasons including a lack of training in pain management, the fear a terminally ill patient will become addicted to the pain medication, the fear that if the patient dies the doctor may be criminally charged, and the biggest fear, that the federal government, which monitors the use of drugs used to treat pain, may suspect the physician of abusing drugs and revoke his or her prescribing privileges.

Better end-of-life care is needed, including better access to pain alleviating drugs, better training of physicians in how to treat pain, relaxed oversight by the Drug Enforcement Administration (DEA) that presently acts as
a barrier for many physicians who want to prescribe high doses of pain medication, and new laws that would hold healthcare professionals accountable for the failure to treat pain. While such changes will reduce the desire for aid in dying, it will not entirely eliminate it. For some patients the only way to relieve pain is through extremely high doses of medication rendering them incoherent or comatose, a situation they find unacceptable. Other patients find that while their pain can be managed, the side effects diminish what quality of life might be left. This can include constant nausea, chronic constipation, severe diarrhea, the feeling of air deprivation or having to depend on life support to keep them alive when they no longer wish to live.

**Do you think it is safer for aid in dying be legally regulated, and if so, why?**

Compassion & Choices believes that regulation prevents abuse and makes sure that only those who actually need assistance receive it. Studies show that in Oregon the rate of assisted deaths under the law is approximately 2.3 per 1,000. Outside of Oregon where it is not authorized, and therefore unregulated, one study found the rate to be 1 per 250, over twice as high. Regulation allows open, versus secretive, communication to take place between the physician and patient, as well as with the patient’s family.

**Why does the law only protect and help people who can physically self-administer the medication?**

The law is designed to make sure the individual remains in control at all times and that no one else, not even that person’s physician, can assist them in the self-administration process.

Ironically, a patient on artificial life support, including one that is not terminally ill, has a legal right to discontinue further treatment even though it is foreseeable that death will result.

In the 1997 case *Washington v. Glucksberg*, Compassion & Choices (then Compassion in Dying) argued that under the 14th Amendment “Due Process” clause a terminally ill person should have the same right to end their life as a person on artificial life support who decides to discontinue further treatment. While two lower courts agreed, their decisions were overturned at the U.S. Supreme Court level. However, the opinion did not say that there would never be a case where such a
right might be found to exist; only that it didn’t find such a right in this particular case.

Why do you say it isn’t “suicide” when a dying person ends their life with the help of a doctor?

Suicide is usually an emotional and irrational act that deprives people of what might otherwise be a full and rewarding life. It is inappropriate to label a competent, terminally ill and dying patient as “suicidal” when that patient, in consultation with his or her physician, has made a rational and informed decision to end their life to avoid prolonged suffering.

Medical experts have discussed in detail why the term “suicide” or “assisted suicide” is inappropriate when discussing the choice of a mentally competent, terminally ill patient to seek medications that he or she could consume to bring about a peaceful and dignified death. In Oregon, Washington and Vermont, where assisted dying is a legal option the cause of death is listed as the underlying illness, not a suicide or “other than natural causes.”

What are some of alternatives to aid in dying? Are they successful?

There are usually several alternatives for patients to consider, for example hospice and palliative care. One Oregon study found that when patients became aware of their other options, about 90% chose a different alternative to obtaining a life-ending medication. What most patients want is the knowledge that an option of last resort is available if all other attempts to relieve their pain or suffering prove unsuccessful. Knowing such an option exists actually encourages patients to try other alternatives.

What are the reasons a person gives for wanting to end their life with aid in dying?

In Oregon, aid in dying has been a legal option since 1998. The following details what patients stated as the reasons for wanting to end their life. Patients often give multiple reasons, and therefore the following is not based on a total response equaling 100 percent.
1. **Loss of autonomy (91.4%)** These are generally people who are fiercely independent and used to being in control. As their illness progresses and they begin to lose control, for example becoming bedridden and dependent upon artificial means of life support, they often find their situation intolerable.

2. **Loss of enjoyment of life (88.9%)** In many cases patients require so much medication to relieve their pain that they see no point in being kept alive. There are also patients who suffer from chronic nausea, vomiting or shortness of breath either as the result of their illness or medications being taken to control the pain.

3. **Loss of dignity (80.9%)** Debilitating illness often require a person to watch him or herself progressively deteriorate.

4. **Loss of bodily functions (50.3 %)** Some people feel it humiliating and degrading to be in diapers, or dependent upon a catheter, or to subject their own children to having to clean up after them.

5. **Being a burden on loved ones (40%)** In most cases the patient wants to avoid situations such as having to move in with their children, having their children turn down career opportunities to become full-time caregivers, or burning-out a spouse or other loved one because of extensive healthcare needs.

6. **Pain (23.7 %)** For some patients whose cancer has metastasized, there is often nothing that can be done to control pain aside from a procedure called “terminal sedation,” where the patient is essentially placed into a coma so they will no longer experience pain. Some patients feel since they are dying anyway, why prolong their life in a state of unconsciousness? Additionally, even where pain can be controlled, side effects such as chronic nausea, chronic constipation, chronic diarrhea, or even being so “doped-up” that the patient cannot communicate were noted to be involved in the decision making process.

7. **Financial concerns (2.9%)** A few patients cite the futility of exhausting their finances to stay alive a few days longer when the money could be put to better use in support of their families, etc.
What are the safeguards under the Oregon, Washington and Vermont Death With Dignity Acts?

The Oregon, Washington and Vermont laws contain over a dozen safeguards to prevent abuse, which include a second concurring medical opinion about the person’s terminal prognosis, multiple requests from the person—two oral and one written, a mandatory waiting period between requests, a third psychological opinion if either physician suspects the patient is being coerced or may not be capable of making an informed decision, and mandatory counseling on alternative forms of treatment and care including hospice, palliative care, pain management and spiritual counseling.

1. The person must be a competent adult (age 18 or over).

2. The person must be a legal resident of the state.

3. The person must be capable of self-administration (only they can take the medication themselves).

4. The person must be terminally ill, defined as someone with an incurable illness who is expected to die within six months or less.

5. A second physician must confirm the terminal diagnosis.

6. If either physician suspects the request for aid in dying is motivated by depression or coercion, a third examination by a psychologist or psychiatrist is required.

7. Only the person themselves can initiate the request.

8. The person must make two oral requests for the medication, separated by a minimum 15-day waiting period.

9. The person must make a third written request, witnessed by two people who know the patient and who can testify, if necessary, that the request was an informed and rational once.
10. At least one witness cannot be related by blood, marriage or adoption, or stand to gain financially from the person’s death,

11. Prior to writing the prescription, the physician must confirm that the person is both still competent and capable of self-administration.

12. The physician is required by law to counsel the person on alternatives to aid in dying, including hospice, palliative care and pain management.

13. The physician must recommend, but not require, that the person inform their family of the decision to accelerate death.

14. No insurance policy or contract can be made invalid if a person uses the law to hasten death.

15. The person can change his or her mind at any time.

16. Any physician, pharmacist or medical facility opposed to aid in dying does not have to participate.

17. If a death occurs under the law the physician is immune from any civil or criminal liability.
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